

# NETWORK NEWS

## News from the Utah Birth Defect Network

January 2006

<http://health.utah.gov/birthdefect>

Volume 3, Issue 1

### Birth Defects: A Lifelong Journey for Children and Families

One baby in 33 is born with a major birth defect. This is a life changing event for many parents and families. It is also the beginning of a lifelong journey with challenges and rewards. In this journey, some families may feel alone or feel they need information and support. At the Utah Birth Defect Network and the March of Dimes (MOD), we recognize this need. For this reason, the Utah Chapter of the MOD is hosting the first annual meeting in January for families of children with birth defects. ***Birth Defects: A Lifelong Journey for Children and Families*** will be held at the Spencer F. and Cleone Eccles Health Education Building, Satur-

day, January 21, 2006, from 1-5 p.m. Kurt Bestor will be the keynote speaker. This meeting is meant to provide support and information for families that have a child with a birth defect. Families will be able to meet, network, and build relationships that strengthen supportive networks. Additionally, we hope this meeting will increase awareness about the frequency of birth defects in Utah.

This meeting is free to any family member(s) effected by birth defects, health care provider or interested observer. Parking will be available in the surrounding parking lots at no cost. Beverages

and food will be provided.

You can do a lot to make this meeting a success:

1. Post this meeting announcement in your office;
2. Register on-line and attend this meeting;  
<http://health.utah.gov/birthdefect>
3. Let families that you think might be interested know about this meeting.

~

Never doubt that a small group of committed citizens can change the world.

Indeed, it's the only thing that has.

Margaret Meade

### January is Birth Defect Prevention Month

January is Birth Defects Prevention Month. Let's take this opportunity to make a difference.

Birth defects are the leading cause of infant death. Every year in Utah, approximately 1,400 babies are born with a birth defect. Medical care, support services, special education, lost wages, and lost productivity just scratch the surface of the financial and emotional impact of birth defects and disability on families, individuals, businesses, and communities.

The good news is that **prevention works**. However, every year we still see children

who are born with birth defects who would have likely been born healthy if a few simple messages had reached all women and were implemented.

**The key to birth defect prevention is optimal health from before conception.** For example, the neural tube, which will form the spine, closes by 4 weeks after conception (two weeks after the first missed period), when many women do not even know that they are pregnant. Taking folic acid supplements, avoiding smoking and alcohol, managing chronic illnesses such as diabetes and seizures, getting immunized -

all of this works if done in time, ideally from before conception.

Because it is difficult to say when one is about to become pregnant (approximately 50 percent of pregnancies in the US are unplanned), the Utah Birth Defect Network (UBDN) encourages preconception care in every aspect of health care for women throughout their reproductive years.

The following prevention strategies can easily be incorporated into any clinical practice:

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# The Craniofacial/Cleft Palate Team (CCPT)

Children born with cleft lip with and without cleft palate, cleft palate, or other craniofacial problems are seen by the Craniofacial Cleft Palate Team (CCPT) at Primary Children's Medical Center in Salt Lake City. Infants and children attending these clinics are seen by a Pediatric Dentist, Cleft Orthodontist (the Director of the team), Pediatric Otolaryngologist, Pediatric Craniofacial Plastic Surgeon, Speech / Language Therapist, an Audiologist and a representative of the Utah Department of Health's Children with Special Health Care Needs. Approximately 450-480 children are seen each year by this multidisciplinary team. About 150 of these are new patients. The majority of the 30 clinics held each year are at Primary Children's Medical Center; clinics are also held in St. George, Ogden and Blanding. Children are evaluated annually by the entire CCPT and an individualized treatment plan is created. These treatment plans are sent to the family, the primary care physician, and the surgeon of record. Referrals are

also made to appropriate specialties not represented on the team during the visit (Genetics, Ophthalmology, Nutrition, Occupational Therapy, Social Work, etc.).

The Nursing Coordinator is the liaison for the families and is responsible for organizing the clinics. The Nursing Coordinator is also a resource for pregnant couples expecting an infant with a cleft lip or cleft palate.

Pregnant women and their partners are encouraged to make an appointment to meet with the Nursing Coordinator after diagnosis. During these meetings an album containing before and after pictures of children with clefts in various stages of repair is viewed and discussed. If a specific surgeon hasn't been requested the Coordinator will help the couple select one and assist them in making contact with that surgeon as well as addressing financial resources. Feeding is discussed and the proper assembly and use of a cleft nipple and bottle is demonstrated. The couple is encouraged

to take the bottle and nipple home to practice and take this to the hospital at the time of delivery.

The before/after photos comfort most couples and seeing the great surgical results gives them hope that their child will look "normal".

After delivery couples have stated that knowing what to expect visually before delivery and knowing they have a surgeon lined up is a great relief. Learning how they will feed their baby and bringing their own cleft bottle and nipple with them to the hospital before delivery gives them the opportunity to enjoy their new baby rather than worrying about these details immediately post delivery.

Prenatal diagnosis of a cleft lip or cleft palate provides the prospective mother and father an opportunity to meet with the CCPT coordinator and minimize anxiety at delivery.

LeAnn Roling RN, BSN

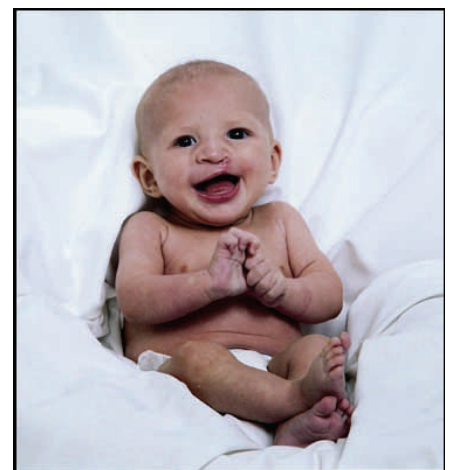
Craniofacial/Cleft Palate Team Coordinator  
Primary Children's Medical Center

## Comments from parents who met with the Nursing Coordinator prior to delivery:

"Meeting with you (Cleft Palate Coordinator) assured us that everything was going to be okay, we appreciated having someone to talk to. The before and after pictures were so comforting compared to what we were seeing on the Internet. And having the opportunity to see our Doctors as a team saved us from having to make all those appointments to see them individually." Kristi H.

"Thanks a bunch for all the help. I think we were well prepared for his birth and that was a great relief." Lisa B.

"I would have been so overwhelmed leaving the hospital (after delivery) if I hadn't met with you and gotten information about what was in store for us. You were my life line." Becky B.



# Adding life to years: exploring quality of life in children with birth defects

"As a nation we have been successful in adding years to life. Now we must add life to years." More than four decades after President John F. Kennedy addressed these words at the 1961 conference on aging, this vision takes on a special meaning for all of us who strive to improve the lives of people with birth defects and developmental disabilities.

These four decades have seen remarkable improvements in birth defect treatment and rehabilitation. As more and more affected people and families expect longer and fuller lives than did preceding generations, issues of quality of life increasingly come to the forefront. Yet, when one searches the scientific literature for good, high quality information, one finds little on quality of life as it relates to most children with birth defects and their families.

At the Utah Birth Defect Network we recognize that quality of life is an important yet understudied issue. With the help of a team of experts in Utah, ranging from clini-

cians, nurses, epidemiologists, and economists, we are now developing pilot studies to begin looking at quality of life among people with birth defects.

These studies are difficult, for several reasons. Quality of life includes multiple dimensions of health. It has to incorporate personal perceptions and values. And it has to be assessed in ways that account for how perceptions change with the growing child.

In our pilot study we will be asking some important questions. How do families and individuals evaluate their quality of life? What aspects are most affected by having a birth defect? What important aspects do current interview instruments cover and which ones do they miss? What can families tell us that can make the future generations of quality of life studies better and more relevant to their needs and their issues?

In this pilot we will focus on craniofacial anomalies, including facial clefts such as cleft lip and cleft palate. There are several reasons

for this choice. They are common birth defects, and even more so in Utah, which has one of the highest rates in the world for facial clefts (1 in every 450 babies). They can lead to considerable illness and disability, because problems with feeding, hearing, and speech. They require surgeries that can be multiple and complex. Their treatment can be costly. And they affect the face, putting affected people at risk for social, personal, and psychological concerns.

These studies are exciting and groundbreaking. They would not be practically or financially possible without the Utah Birth Defect Network. It is because of UBDN's structure, data, and cooperation with medical and public health professionals and families, that we can be evaluating and addressing these important issues for all families in Utah. We look forward to these activities and to your help and support.

Lorenzo Botto, M.D.  
Medical Epidemiologist  
Utah Birth Defect Network

## January is Birth Defect Prevention Month Cont.

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**1. Promote folic acid education and consumption as a standard of care.** The U.S. Public Health Service recommends that all women of child-bearing age consume a multivitamin that contains 400 micrograms (400 mcg or 0.4 mg) of folic acid every day, to reduce the risk of having a pregnancy affected by a neural tube defect. It is estimated that taking folic acid would prevent at least 50-70% of all neural tube defects. However, according to the Utah Behavioral Risk Factor Surveillance Survey, **less than half (48%)** of Utah women in 2004 consumed the recommended amount of folic acid daily. Consumption was lower among Native Hawaiians, Pacific Islanders, and Hispanic women.

**2. Ensure that women with chronic illnesses are optimally managed**

**a. Women with diabetes should be under strict glycemic control prior to conception.** Poorly controlled diabetes increases the risk for major birth defects twofold, and the risk for severe heart defects eightfold. Strict glycemic control from before conception reduces these risks.

**b. Women on potentially teratogenic medications should know about the risks and offered safer medications when considering pregnancy.** For example, valproate, which is used for seizure dis-

orders, increases the risk for neural tube defects (spina bifida). There are other options for women considering pregnancy, which should be discussed with their doctors.

**c. Women with other chronic conditions (e.g., high blood pressure) should work with the health care providers to ensure that the underlying condition and medications are optimally managed.**

**4. Optimize medication use in pregnancy.** Many effective medications are safe, a few are harmful, and for several we have little information. Taking a teratogenic medication or not taking a safe medication when needed in pregnancy can both be harmful. The best way to obtain the latest information and expert advice is through the **Pregnancy Riskline (1-800-822-2229)**

**5. Promote healthy habits in women considering pregnancy and during pregnancy**

**a. no alcohol:** there is no known safe dose for alcohol.

**b. no smoking:** smoking increases the risk for birth defects, low birth weight, and sudden infant death.

**c. keep fit and maintain a healthy body weight.** Increasing data suggest that women who begin a pregnancy while overweight or obese may be at increased risk for having an affected pregnancy

**6. Know your patients' history.** A family history of birth defects is one of the strongest risk factors for having an affected pregnancy. But something can be done. For example, **higher doses of folic acid** are effective in reducing spina bifida risk also among women who have already had an affected pregnancy. Evaluation by a genetics professional (e.g., a genetic counselor) can help provide further information and risk evaluation.

You can make a difference today in the lives of Utah families and communities. The UBDN in conjunction with the National Birth Defect Prevention Network has created fact sheets on folic acid, domestic violence, diabetes, healthy lifestyles, infections and immunizations, medical conditions, and smoking for your use in English and Spanish. These fact sheets can be ordered by contacting the UBDN.

Our hope is that you will make an effort to incorporate these prevention messages into your clinics. Should you have questions about or like more information sent to you, please contact me, Amy Nance.

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Place Label Here

Check out our new web-site!  
[www.health.utah.gov/birthdefect](http://www.health.utah.gov/birthdefect)

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# Save the Date

## Birth Defects: A Life Long Journey for Children and Families

Keynote speaker: Kurt Bestor

January 21, 2006 1-5 p.m.

Spencer F. and Cleone Eccles Health Education Building

Register online at: [www.health.utah.gov/birthdefect](http://www.health.utah.gov/birthdefect)

Attendance is free!

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